

Stigma Hurts:

Stigma, Stigma Injury and the Language of Dignity

Katie Bell MSN RN-BC CARN PHN
Telewell Indian Health MAT Project
Tribal MAT 2.0

Bell2020



Stigma Injury

- *Imagine what it is like for a person who has suffered from a severe substance use disorder for decades encountering stigma at every door: a secondary injury has occurred from the seeking of help - a Stigma wounding or Injury.*



What common feelings drive the stigma directed at people with substance use disorders?

- ▶ **The substance use disorders in our families.**
 - ▶ Family shame passed through generations
- ▶ **Anger/frustration**
 - ▶ “Why can’t they just stop?” – Family and friends are baffled and frustrated.
 - ▶ Relapse is disappointing and often devastating
- ▶ **Fear**
 - ▶ Early tragic death related to alcohol and drugs
- ▶ **Loss, Hopelessness and grief**
- ▶ **12 Step, cultural and religious rules**
 - ▶ Sin and moral failing – perception that the person with substance use disorders
- ▶ **Behaviors and consequences can be difficult and destructive.**

A Guide to Acronyms and Terms

- ▶ **MAT** – Medications for Addiction Treatment or Medications for Opioid Use Disorder (MOUD)
- ▶ **OUD** – Opioid Use Disorder
- ▶ **StUD** – Stimulant Use Disorder
- ▶ **Stigma** – barrier to care communicated by language, judgmental attitude and because of this judgment, decrease in quality of care.
- ▶ **Misuse** – replaces the word abuse. Taking more than prescribed, using non-prescribed opioids including injectable heroin and fentanyl.



Addiction or Substance Use Disorder?

- **Addiction is a chronic, progressive, relapsing disease. We use this term in Medicine. – American Society of Addiction Medicine**
- **Substance Use Disorder – in Behavioral Health (DSM-5) measured on a continuum of mild to moderate to severe. Opioid Use Disorder, Stimulant Use Disorder, Alcohol Use Disorder. etc.**



Opioid Craving

- **“We need three things to survive (besides oxygen): food, water and dopamine. If you deprive study subjects of water for three days, then put them in a functional MRI and place water on their lips, the relative size of the craving is like a baseball. Do the same with food, and it is like a basketball. ...Then, take someone with an addiction to opioids, *up to one year after their last use*, and talk about OxyContin while they are in a functional MRI, and the relative size of that craving is the size of a baseball field.” (Corey Waller MD, 2016)**

Craving



Opioid Dependence + Behaviors = Opioid Use Disorder

Opioid Dependence is Physiologic
– tolerance causes need to
increase quantity to sustain effect;
withdrawal symptoms when opioid
is stopped.

Addictive Behaviors involve misuse
such as taking more than
prescribed or continued,
compulsive use in the face of
increasing consequences to health
and wellness, diversion and relapse
driven by craving and triggers.



Understand trauma as a common root cause of addiction

- ▶ “The question is not why the addiction, but why the pain.” And the source of pain is always and invariably to be found in a person's lived experience, beginning with childhood – Gabor Mate MD
- ▶ Adverse Childhood Experiences – ACEs
- ▶ Adult trauma related to lifestyle of drug and alcohol use.
- ▶ People with trauma need to feel safe.

Why opioids?

- ▶ Opioids change the perception of pain – this includes the numbing of physical pain, emotional pain and mental anguish. People with untreated trauma can self-treat (let's not use “self-medicate”) their pain with opioids.



Stigma is our biggest barrier to ending the opioid epidemic

- Stigma is shaped by our thinking – a bias and perception that substance users are bad and immoral rather suffering with a chronic condition requiring care and treatment.
- Stigma is communicated by words and language, tone, interpersonal attitude, indifference and body language.
- Stigma becomes internalized by the person seeking help. The person views themselves as bad or weak which fuels the shame of stigma.



Stigma in its many forms

- ▶ **Institutional and Structural – political will and funding for treating Substance use disorders**
 - ▶ **Congressional allocation of funds – slow response to the epidemic and underfunding is a part of our reality in providing care**
- ▶ **Medical Care settings – contempt and decreased care time from medical providers in Emergency Dept, Hospital and Primary Care settings (Yes! Things are changing but we have a long way to go. Thank you, California Bridge program.)**
- ▶ **Law Enforcement and Justice System – jail without drug and alcohol treatment. Withdrawal management can be “old school” and unkind.**



Stigma in its many forms

- **Ethnic cultures and families** – family shame, religious rules and perceptions. Many generations impacted by family substance use and secrecy. We learn about this shame early in our lives.
- **SUD Treatment settings** – “when are you tapering off your suboxone?” was once a common part of the counseling care.
- **Recovery Settings** – 12 Step groups more accepting but not considered “clean” if prescribed methadone and buprenorphine for OUD addiction.
- **Medication Assisted Recovery Anonymous (MARA)** – a welcoming 12 Step program for those receiving medications for addiction and behavioral health diagnoses.



Stigma contributes to poor care

- ▶ “Health professionals may have an avoidant approach to delivery of care with substance use disorder patients compared to other patient groups may result in shorter visits, expression of less empathy, and less patient engagement and retention.” (Kelly, 2016)
- ▶ These *negative stereotypes* guide social action, public policy and the allocation of health-care expenditures. Therefore, people with substance use disorders may experience stigma because of the culturally endorsed stereotypes that surround the health condition.

Stigmatizing language no longer used

- ▶ “Abuse” as in Substance Abuse. Was identified as the only diagnosis which had the word abuse. “Misuse” or “Use”.
- ▶ “Addict” – rather, *person with substance use disorder* or *people who inject drugs* or *people who use drugs*. “Addict” is still used in 12 Step culture as a part of the recovery process.
- ▶ “Drug-seeking” – can be re-framed as “relief-seeking”. Focus on the person rather than the behavior.
- ▶ Needle Exchange – Syringe exchange – essential aspect of
- ▶ We use people first language: “people with diabetes”, “a person with schizophrenia”, “people who use drugs”, “a person with alcohol use disorder”.

Urine Drug Screens - Labs

- ▶ In medicine and all places of care, we do not refer to lab results as “clean” or “dirty”, we always use medical language to support the dignity of our patients.
- ▶ If we say “Positive” or “Negative”, we need to be specific: “positive for opioids” or “positive for methamphetamine” for example.



The Stigma Injury

- Often after years of stigma in settings designated for care, a person will not seek help or even basic medical or dental care.
- Symptoms can be fear of Emergency Departments, distrust of medical providers; feelings of shame and dishonesty.
- If not treated, the person internalizes the shame and low-self worth caused by stigma





The Stigma Injury – how to treat

- Openly and directly acknowledge and validate the experience of stigma and how stigma has contributed to their suffering. *Humility expressed by medical providers and care teams is a balm to the stigma injured.*
- Language of Dignity begins with listening. Followed with respect.
- Develop trauma-informed care and understand that stigma itself is traumatizing for people seeking help. For some it has been decades of disrespect, harsh judgements and minimal care.
- Stay focused on the human being and bring respectful, compassionate interventions.
- Partner with our patients. Build a trusting relationship and support autonomy.
- Keep the doors open to care in the face of relapse. "This door will always be open to you."



Allie

Allie is a 19 yo woman presenting to the Emergency Department in her small hospital in her rural community with complaints of severe earache. Allie has hesitated for days to seek help as she overheard a staff member refer to her as the addict in Bay 3 at her last visit there. This is the only hospital in her small town, and she has been coming here for emergency care most of her life. Recently, she has had more recent visits, including treatment for a heroin overdose about 6 months ago. As she is brought to her bay in ER, she hears someone on the staff refer to her as a frequent flyer.

As the new RN reviews her chart and her current symptoms, she sees a recent positive test for pregnancy, and asks if she is still “shooting drugs”. The wait for the MD to see her is long and she is beginning to feel the onset of opioid withdrawal. The lab results return and when the MD comes in, he begins with, “CPS will take your baby if you don’t get clean. Your drug screen is dirty today. Now, why are you here today?” MD prescribes antibiotics for ear infection and refers her to follow up with her primary care.



A recent quote from a recovering person

“The stigma is the main reason we don’t continue treatment indefinitely. When we are seen as bad, we want to get good as fast as we can and when the job is done, we want to distance ourselves from things and places that make us look like bad people. If we can be seen as sick and brave for fighting a terrible and fatal illness our numbers would be so much better.” - Steve



**NO MORE
STIGMA. NO
MORE SHAME.**



Naloxone – a PSA

- ▶ **With the increase of opioid overdose deaths since the CoVID-19 – we must increase Fentanyl Awareness and access to naloxone (NARCAN).**
- ▶ **Prevalence of Fentanyl in our communities**
 - ▶ **Mixed with other substances such as methamphetamine, cannabis, heroin, street pills**
 - ▶ **50 -100 more potent than morphine**
 - ▶ **Can require up to 6 doses of naloxone (NARCAN)**
 - ▶ **California Naloxone Distribution – go online and order for you agency to distribution.**
 - ▶ **NARCAN NOW app – has complete training and all relevant info for saving a life.**

References and links

- Naloxone Distribution Project: https://www.dhcs.ca.gov/individuals/Pages/Naloxone_Distribution_Project.aspx
- California Bridge Project: <https://www.bridgetotreatment.org/cabridgeprogram>
- **Medication Assisted Recovery Anonymous (MARA) – a welcoming 12 Step program for those receiving medications for addiction and behavioral health diagnoses: <https://www.mara-international.org/>**

- **Barry, C.; McGinty, E.; Stigma Reduction to Combat the Addiction Crisis — Developing an Evidence Base. 2020. *New England Journal of Medicine*.**
- **Volkow, N., Collision of the COVID-19 and Addiction Epidemics.2020. *Annals of Internal Medicine*.**
- **Volkow, N., Stigma and the Toll of Addiction. 2020. *New England Journal of Medicine***